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ABSTRACT

This monograph provides a Canadian perspective on ways in which women with disabilities have been excluded from research, suggests a framework for research for and with women with disabilities, and presents guidelines for stereotype-free language. It also considers the role of research in society, comments on research methods, and considers ways of communicating about women and disabilities. It stresses the need for researchers to work for and with women with disabilities. Research areas of concern to women with disabilities are identified: employment, poverty, health, violence against women with disabilities, mothering, self-image, and reproductive technologies. Specific recommendations are made for research guidelines regarding values (e.g., generation of research questions by women with disabilities through advocacy organizations); methodology (e.g., disabled women should be involved as consultants when research tools are being developed); dissemination (e.g., women with disabilities need publishing grants and sponsorship to attend and organize conferences). A glossary of 15 research terms, a bibliography of 18 items, and a list of 11 books available from the Roeher Institute are also provided. (DB)

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RESEARCH
BY / FOR / WITH
WOMEN
WITH
DISABILITIES

The Roeher Institute

A straightforward version of:

Research From the Margins: Issues in Research For and With Women With Disabilities
by Aileen Wight-Felske, PhD, for The Roeher Institute, 1990

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OVERVIEW

The purpose of this paper is:
1) to make the reader think about knowledge and how it is used in society;
2) to make the reader aware of the ways in which women with disabilities have been excluded from research;
3) to outline a framework for research for and with women with disabilities;
4) to comment on research methods;
5) to present guidelines for stereotype-free language;
6) to look at ways in which we can tell people about women and about disabilities.

RESEARCH IS IMPORTANT

Research is a powerful process for learning about and understanding the world. Universities are an important centre for research activities. In Canada, universities have been criticized for the limited research on the life experiences of women, people with disabilities, natives and elderly Canadians. They have been left out of research, both as participants and as people conducting the research.

University researchers need to learn to work *for* and *with* women with disabilities if they want to address this gap in knowledge. Canadian women with disabilities want research which will address their lives and reflect their concerns. Consultation with women with disabilities will enable this to happen. Research is an important tool for advocacy groups in their struggle for social change.

"We are ... the sources of the research. We have the knowledge and we have the understanding of the life of being a woman with a disability." (Women and Disability Research Forum, 1988)

The purpose of this paper is to raise the awareness of researchers, in the area of women's studies and in the area of disability research, to the social reality of a "formerly silenced" group: Canadian women with disabilities.

UNDERSTANDING RESEARCH

Research is a way of discovering knowledge through the systematic study of a problem. This implies, first, that research is *one* way, and not the only way, to discover knowledge; second, that research is a systematic process; and third, that research is problem-oriented.

There are two different ways in which people think about research to acquire knowledge. *Quantitative* researchers measure their topic of study by numerical means. They tend to include large numbers of people in their studies. Federal census data, such as the Health and Limitation Survey of 1987 (HALS) is an example of quantitative data, and research reports can be drawn from it.

Qualitative researchers believe that individual people have different experiences and different ways of knowing. They are interested in learning how people see each other in their culture. Feminist researchers largely view social knowledge from a qualitative point of view (Harding 1987). The book, *Voices from the Shadows: Women with Disabilities Speak Out* (Matthews, 1983), is an example of qualitative research.

Both quantitative and qualitative researchers can make important contributions to knowledge about women with disabilities.

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RESEARCH QUESTIONS

"The point of research is not only to document the condition of women's (with disabilities) lives ... its a starting point ... We want to change the conditions, we want to radically restructure society ... (to) improve our lives." (Women & Disability Research Forum, 1988)

Traditional researchers have been criticized for not looking at questions women with disabilities believe are important in their lives. For example, the role of gender (male/female differences) in disability has been ignored by researchers. This is a critical factor in research for women with disabilities. They are societally marginalized due to their handicap and due to their role as a woman (nurturer, child bearer).

Some research questions place the people in the study at risk, legally, physically and ethically. Studies on the use of punishment as a form of behavioural control, for example, are viewed by some researchers as unethical. Other topics may give the appearance that women with disabilities are victims.

In disability research there are two kinds of questions asked:

1) *The more traditional rehabilitation researchers view disability as a problem in the person and ask questions focused on individual therapies.*

2) *Consumer advocate groups view disability as a societal problem and ask questions focused on social change.*

Researchers should ask questions from the view of women's life experiences: the way women live, their opportunities, the way they think and act. They should focus on questions regarding the way in which society is structured to exclude and devalue women with disabilities and how this can be changed.

Questions structured to bring about a positive change in peoples lives belong to what is called "social action" research.

Research studies such as the DisAbled Women's Network (DAWN) Position Papers (1989) are good approaches to topics such as violence and sexual abuse because the researchers are women with disabilities. This establishes a view of women with disabilities as leaders in change. When women are not involved in research they are at risk as unknown and undervalued people.

Research areas of concern to women with disabilities are:

i) **employment**
ii) **poverty**
iii) **health**
iv) **violence against women with disabilities**
v) **mothering**
vi) **self-image**
vii) **reproductive technologies**

Women in institutions have been excluded from research. If they were to be included in research the questions asked of this powerless group must be asked carefully and monitored by advocacy groups. The focus should be on positive change in their lives.

RESEARCH PARTICIPANTS

"Women with disabilities need to maintain control and direction over the research although other people who have the resources may actually be doing the work." (The Women and Disability Research Forum, 1988)

Simply adding women as subjects in research does not adequately address all problems in traditional research, as it suggests that only the research questions generated by researchers (male) are important. Further, women's experiences are varied; experiences from women of different income levels, races and cultures must also be addressed. There is no generic woman.

> "One thing women, people with disabilities, and other devalued groups in society share is the experience of being marginalized in society, cut off from ways to participate in decision making." (Kirby & McKenna 1989)

A similar problem arises when researchers simply add disability as a research category. Disabling conditions include a wide range of physical and mental handicaps and limitations, and maner of onset of disabilities. Other differences may include age, marital status and sexual orientation. This does not result in a commonality of experiences among women labelled disabled. Social, physical and economic barriers affect women in varying ways and to varying degrees. Since women with disabilities are not a homogenous category, research questions must recognize the differences. Research by, for and with women with disabilities must also take into account issues related to minority ethnic and racial concerns

Research questions regarding social action and power, however, can be framed from a cross-disability perspective.

THE RESEARCHER

Traditional research has viewed the researcher's beliefs and values as separate from the research process. This has resulted in a process of powerful people studying powerless people from the outside.

When judging whether a study is worth funding, or when evaluating research findings, it is important to know and take into consideration: who are the researchers and what are their beliefs and values? A researcher's background influences the kinds of questions asked, the way the study is conducted and the way the findings are written. For example, if a study on birth control is funded by a drug manufacturer who produces birth control pills, knowing this may change how you view the results. This is true of all research, regardless of the type.

> It is important that researchers do not use their own experiences as a way to interpret the subject's life.

A feminist view of "ways of knowing" is based on the belief that the researcher's beliefs and values affect their findings. The researcher should speak with participants who are "knowers" of the experience. Often the researcher is a member of the group being studied or has spent considerable time with the group members. This way, the research process is one of equals learning together.

TYPES OF RESEARCH

It is important to choose a research methodology appropriate to the questions being asked.

A research methodology is the technique used by the researcher to gather evidence. Different research methods have particular strengths for different kinds of questions and answers. The type of investigation method used in a research study is revealed by the research name: experimental, descriptive, case study, correlation or survey. These terms are defined in the glossary on page 14.

A feminist view of research asks researcher and participant to define together the method of information gathering will be used. There are five methods of gathering data:

1) interviews,
2) surveys,
3) participant observation,
4) life histories,
5) studying public or private documents.

One important assumption in research is that data collection is non-exploitive. Women with disabilities must be able freely and knowingly to choose to participate in a study. For example, women with disabilities who have been sexually abused are often "subjects" of reports by researchers, yet researchers are not held accountable for the impact of participation or for ensuring that the research leads to positive change in social conditions for the participants.

Research should occur in a setting with an equal relationship between the researcher and the participant. In social action research, the interviewer interacts with those whose lives are being researched; they "hear the participant into speech" (Finson, 1985). The researcher may conduct group interviews, and is not limited to individual data collection. It is often necessary to repeat data collection.

LANGUAGE USED IN RESEARCH

Language is power in Canadian society. The words used to describe people give us value, e.g. "millionaire", or take value away, e.g. "single mother". Labels put on people are used to create boundaries and separate those with power from those without. Gender-free language should be a requirement of all research proposals. The common use of "girls" in research to refer to women with disabilities is unacceptable.

> People who are negatively labelled say, "we are often required to perform a kind of doublethink/double-speak in order to translate our experience into the concepts and language of the status quo". (Kirby & McKenna, 1989)

Similarly, disability stereotyping language cannot be used to define participants in research. For example, the labels used to describe people in some rehabilitation services such as "the retarded", disempower them in relation to people who do not use such services.

The language of research must change. It is important that language be accessible and free of gender, ethnic, racial and disability stereotyping. *A Way With Words* (1990), published by the Department of the Secretary of State, Canada, provides guidelines for language use in terms of disability. The words used to describe disability, such as, "cerebral palsied"or "mentally retarded", are often outdated, inaccurate and stem from fears and misconceptions. It is never appropriate to identify people solely by their disability. Identification is given by phrasing such as "people with cerebral palsy" or "people who have been labelled mentally handicapped". The term "patient" is often used inappropriately; being disabled is not the same as being ill. Reports should omit the word patient except in reference to doctor or hospital situations or when someone is actually ill.

GETTING THE WORD OUT

"Those in power ... decide what book gets published, what research is funded and what knowledge is legitimated." (Kirby & McKenna, 1989)

The publication of research *for/with/about* women with disabilities is a critical factor in "owning" knowledge. Rehabilitation researchers have been criticized because their research findings are not easily accessible to consumers, people with disabilities and their families. Publications produced by advocacy organizations such as the Canadian Association for Community Living and the Coalition of Provincial Organizations of the Handicapped have included women's issues (e.g. the *entourage* journal and *Compass* magazine). Women's publication venues have included articles on women with disabilities, for example, at conferences (C.R.I.A.W 1990) and in journals (*Resources for Feminist Research*).

Researchers should include plans for getting their work to the public in their funding applications. This includes large print, braille, audiotape and language translations, as well as presenting research at gatherings where women with disabilities meet. Plans should also include funding women with disabilities to attend conferences.

CONCLUSION

"It is our vision that the next decade will see an explosion of research for and with women with disabilities." **(Comité de Liaison Committee, June 1991)**

In this paper questions have been raised to challenge researchers who are choosing topics, deciding how to conduct their study, seeking funds and telling others of their findings.

At present there is very little research about women and disability. This is a signal that it is not viewed as important by researchers and funders. Changing this situation is a critical advocacy issue.

It is our vision to create a future where knowledge of women and disability gathered from researchers, using a variety of methodologies, will be published, presented at conferences, and used in defining public policies which affect all Canadians.

RECOMMENDATIONS FOR RESEARCH GUIDELINES

Values:

- Research questions should be generated by women with disabilities through advocacy organizations which represent them. Their topics should be presented to research funders as priorities.
- The researcher or team of researchers submitting funding applications must include a statement of their value base in the research proposal.
- All funding sources for research programs should be given.
- A consultative partnership with advocacy organizations for women with disabilities should be demonstrated by research applicants. Advocacy organizations *per se,* are not appropriate for this partnership, unless the organization has a distinct women's caucus and consultations are with this caucus.
- Research should be sensitive to issues of minority ethnic and racial groups.

Methodology:

- Disabled women should be involved as consultants when research tools are being developed.
- Research questions regarding women with disabilities should be generated in partnership with women with disabilities.
- Researchers who are members of the marginalized group should be viewed as the most appropriate leaders of social action research.
- Advocacy organizations of women with disabilities should serve on review committees which make formal assessments of the risks to participants of proposed research studies.
- Researchers should be aware that the simple addition of women with disabilities as research subjects in traditional research projects does not result in valid research findings about the participants.
- Research methodologies which involve groups as well as individual responses should be legitimized.

- Women in settings which place them at extreme risk, such as institutions, should not be used as research subjects in studies unless the study is directly focused on improving the quality of their lives. There is doubt about the validity of consent provided by participants in research studies who reside in segregated institutionalized settings. Any research involving this highly marginalized group must have a community-based advocacy group monitoring the study.
- Guidelines for reporting on and writing about people with disabilities must be free of gender, ethnic, racial and disability stereotyping.
- An emphasis on action/participation research projects by funders can aid in the validation of knowledge by and with women with disabilities.

Dissemination:

- Women with disabilities should be supported in information dissemination by receiving publishing grants, and receving sponsorship to attend established conferences and to sponsor conferences themselves.
- Researchers must include, in their application for funding, plans for equality of information dissemination, including large print, video and audiotapes, braille and other forms of alternate media.
- The cost of disseminating research, and possible applications of the research to consumer groups, should be included in the research proposal.
- Funding should made be available to conference planners who include women with disabilities in their programs.
- Funding agencies should provide bursaries to women with disabilities to enable them to attend research conferences, both as presenters and as audiences, to increase their ownership of knowledge.
- Scholarships and support monies should be made available to allow women with disabilities to gain entrance to university-level graduate studies in various disciplines.
- Networks of women in academia and in advocacy groups should be created and strengthened to support each other in increasing their knowledge of other women.

Overall:

- The development of partnerships in research, both between individual study participants themselves, and between provincial and national advocacy organizations of women with disabilities, is stressed.

Glossary of Research Terms

Applied Research - provides answers to clinical questions, e.g. program evaluation; determining the effectiveness of a program.

Social Action Research - contributes simultaneously to theory and practice; involves the potential users of the information in doing the research.

Basic Research - designed to answer general, long range questions about human behaviour.

Collaborator - a person who does not necessarily have research experience, but who has a wealth of experience in relation to the research question; one who can greatly assist the researcher.

External Validity - generalization of the findings.

Internal Validity - whether the instruments or procedures measure what they are supposed to measure.

Interview - a guided conversation in which the goal is to elicit from the interviewee rich, detailed materials that can be used in qualitative analysis.

Life History - the experiences and definitions held by one person, one group or one organization as this person, group or organization interprets those experiences.

Method - techniques for gathering evidence.

Paradigm - what is to be studied and what rules are to be used.

Participants - Individuals in research studies about whom data is being collected. They are sometimes referred to as research subjects.

Reliability - repeatability of the findings.

Research - gathering and making sense of information and acting responsibly with the information.

Survey - the systematic collection of data through the use of the interview or the self-administered questionnaire.

Qualitative research - investigation methodologies described as ethnographic, naturalistic, anthropological, field research or participant-observer research.

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Useful Books

Here is a list of books that you can get from The Roeher Institute. The books have useful information for people with a mental handicap, and for their families and friends.

•**Changing Canadian Schools**: Perspectives on Disability and Inclusion. (1991)

•**The Right to Read and Write.** (1991)

•**Take Action — Stand Up For Your Rights**: Self-advocates and the British Columbia Human Rights Act. (1990)

•**The Right to Have Enough Money.** (1990)

•**Righting Wrongs**: Disability, Your Ombudsman and You. (1989)

•**Making Friends**: Developing Relationships Between People Who Have a Disability and Other Members of the Community. (1990)

•**Income Insecurity**: The Disability Income System In Canada. (1988)

•**Poor Places**: Disability Related Residential and Support Services. (1990)

•**The Power of Positive Linking**: How Families Can Empower People Who Have Mental Handicaps Through Mutual Support Groups. (1989)

•**Leisure Connections**: Enabling People With A Disability to Lead Richer Lives in the Community. (1989)

•**entourage**: A magazine about how people can get support in the community to live, learn, work and have fun. It comes out 4 times a year.

The Roeher Institute

At The Roeher Institute, many people are working to make things better for Canadians who have a mental handicap. Many self-advocates help and advise the people at The Institute.

What are the aims of The Institute?

There are ***two aims***, mainly.

1. Finding ways to make sure we can live, and work, in our own communities.
2. Helping to spread the right ideas so everyone in the community is up-to-date about what we really need.

How does The Institute do its work?

There are ***five ways***, mainly.

1. Doing ***Research***. Especially into what works best for most of us. And also into ***funding***. How to get that ***extra*** money that we need.
2. ***Publishing*** the results of the research, and so ***influencing*** choices that affect us.
3. ***Training*** people so they understand our needs better. Things like our human rights and other things that are important to us, such as being educated in the community, and supported work.
4. Providing ***Up-To-Date Information*** to the public, professionals and community groups.
5. Sending out our magazine, **entourage,** four times a year.

Canadian Association for Community Living

The Roeher Institute is sponsored by the Canadian Association for Community Living. This is the organization that brings together 400 local groups with one group from every province and territory to work for us.

For more information, please write to us at:

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You're welcome to phone The Institute at: **(416) 661-9611** if you have any questions, or you want to contribute your thoughts and comments.